



## Dental Stories 2014-15

In an effort to highlight the need for sedation/anesthesia dentistry as well as past and current access to care issues, SCDD solicited dental stories from around the State. Identifying information has been removed throughout these stories. Dentist, hospital, and regional center names were left in – as that may be helpful information. Some stories were edited for clarity, others were left as submitted by parents. The majority of the stories were submitted from the Sacramento area, although some stories were submitted from around the State. Original submissions with contact information are maintained at SCDD Sacramento Office.

Submitted by  
Sonya Bingaman, Manager, Sacramento Office  
State Council on Developmental Disabilities  
2033 Howe Ave. Ste. 160, Sacramento, CA 95825  
[Sonya.bingaman@scdd.ca.gov](mailto:Sonya.bingaman@scdd.ca.gov)  
916-263-3085  
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## Story #1

Hello – my name is Beverly and I am writing on behalf of my daughter Kristy, who has profound autism. She is now 25 years old and lives in a (wonderful) supported living environment in Crescent City. So she lives in Del Norte and her family lives in Humboldt. She is unable to speak very well and could not answer questions, but my phone number is here and you can call me if you need to call.

Kristy has always needed to be anesthetized for her dental work. When she was little, we lived in southern California, and our ONLY option was at Loma Linda University Dental Center. We would often wait a whole year or longer for an appointment. All the appointments were at 8:00am and the waiting room would be full of severely disabled adults and children, WAITING ALL DAY to be seen. It happened at least once that after waiting all day with a very disturbed and upset autistic little girl, they would tell us they had no more time and we had to drive home (an hour and a half) without even being seen.

We moved here to Northern California eight years ago. The biggest problem here (as everywhere) has been getting in to see a dentist that takes Medi-Cal and will work with anesthesia. We were told there was only one in a four county area. Again, there was a year-long wait. HOWEVER, once we went to the St. Joseph's Day Surgery Center in Eureka, we had a really wonderful experience. They were right on time, they treated Kristy very gently, they were kind to her (and to her anxious parents), everyone was very efficient and professional and KIND. The dentist would come out and tell us what had to be done, and then later would tell us how it went. It was a very warm, home-like atmosphere that really helped Kristy to relax. Getting an appointment still takes a year. Our last appointment was at the hospital in Eureka, not at the day surgery center, and it was a far less pleasant experience for Kristy – sterile hospital setting, scary to her. She had to come to Eureka all the way from Crescent City, because this was the only place it could be done.

Like many autistic and developmentally delayed children, it has never been easy to help Kristy with dental care. It is a struggle – she has soft teeth, and when she was little she also had pica, making things even worse. When her teeth needed work, it took so long to get seen that every little problem became a major problem. Sometimes the dentist or his staff would berate us as parents and blame us for her dental problems. When you have a child who takes care 24/7 just to keep her safe and to keep her from running off and to keep her from banging her head into a wall – well, sometimes brushing her teeth three times a day every day for fifteen minutes just cannot be the priority. Doctors and dentists need to know that parents do the best they can, and not just holler at parents. At St. Joseph's Center, we never ran into this sort of condemnatory behavior, but we got it a lot when she was little. At St. Joseph's the staff has always been kind to us and to Kristy. The only problem is access. If we want to schedule an appointment every two years, then we have to ask for one as soon as she finishes one.

## **Story #2**

I am writing about the current crisis in the access to anesthesia or hospital dentistry resources for our clients at Harbor Regional Center (RC). I am the dental consultant for this RC. It is very discouraging to see our veteran dentists that we've had a relationship for years decline to see our clients due to the maze and challenges, refusal of TARs, slow or no reimbursement, and "red tape" most of which makes no sense. This is a huge issue that must be addressed by Sacramento – now. Our clients have no voice of their own in fighting this, but rather we are their advocates to achieve dental care and most of it being under general anesthesia. The few dentists who are willing to reach out and extend their licenses and train specifically for general anesthesia are plainly giving up. Why, because of the bureaucracy of getting the work approved and then reimbursement is so very challenging. This truly is not fair and I am writing in support of addressing this issue and solution.

Just remember that intellectual disabilities is non gender specific, non ethnic specific and can affect anyone in the population. Be grateful for your good health and the good health of your families, especially now that the holidays are here.

Thank you for listening. I anxiously look forward to a change in policy in addressing oral health access to anesthesia, hospital dentistry, and adequate reimbursement, for individuals willing to work with people with developmental disabilities. We need your help – now.

## **Story #3**

My name is Patrick. I'm an administrator for the Federal Courts in a Southern Ca. city. I also have a fifty-one year old autistic brother, Terry. Once or twice a year, I'll take a day off from work, and my mother (who is now in her 80s ) and I will take my brother for a dental checkup and cleaning. Most of the time, we've had to go to a facility in Diamond Bar, which is some 85 miles away from my mother's home in Oceanside and about 115 miles away from my house in San Diego. We get on the road very early in the morning and usually arrive before dawn. When we get there, there is always a line of people outside, waiting for the facility to open. Most of the time, there are van loads of developmentally disabled adults waiting to get in to see the dentist. According to the care givers who bring them to the facility, many of these DD adults are going to see the dentist for the first time in many years, and for some, it's their first time ever. The check-in process which involves several tests and a whole lot of waiting always takes several hours. Finally, by the time my brother is given a bed, anesthetized, seen by the doctor, wakes back up and is ultimately released, it's the early afternoon. Now we can begin our long drive back home...

It's truly remarkable how many patients this facility in Diamond Bar services every day. Especially when you consider that many of these patients have not had much (if any) dental care throughout their lives and they aren't always the most cooperative patients in the world. It's also remarkable the great distances people are willing to travel, and the hardships many involved with DD adults are willing to endure, just to insure these people receive basic dental care. There really need to be more facilities like this made available throughout the state;

adequately staffed with people knowledgeable about DD adults and professionally credentialed.

Probably the most telling statement I heard about the current situation came from Dr. Brian Adams who is in charge of the Diamond Bar facility. He said, he takes care of DD adults' dental needs truly because it is his passion. He certainly does not do it for the money. He says, the way the system works now, he could make a whole lot more money taking care of prisoners' teeth in jail. I think that statement says it all, there is something really wrong with the status quo.

Thank you for your time.

#### **Story #4**

Counties: Los Angeles and San Diego

Age: 51

This is my story of navigating the dental system that has provided for my developmentally disabled son for the past forty plus years. Because of the severity of my son's disability, he has had to be given anesthesia before any dental work can be done on him. He was born in Los Angeles county and we moved to San Diego county 25 years ago.

The following is an outline of our journey since the 1980's through both counties to accommodate his needs.

1980's - USC School of Dentistry

1990 - Dr. Macopolus, DDS

Alverado Hospital, Escondido

1990's - Brian Adams, DDS

to Palomar Hospital, Escondido

2010 San Diego Hospital, SD

Pomona Hospital, Pomona

Diamond Bar Surgery Center, Diamond Bar

(Dr. Adams had to leave these hospitals after one year because of funding issues.

Then, he opened a Surgery center to accommodate his many DD patients.)

2011 - Bruce Adams, DDS

San Marcos

(Doctor did Terry's procedure in his office with an Anesthesiologist in attendance.)

2013 - Tony Georgiades, DDS, APC

Promise Hospital, San Diego

2015 - Awaiting appointment with Dr. Georgiades.

I hope this alerts the powers that be that our system is as broken and troubled as my trail has been in searching for dental services for my son through southern California.

### **Story #5**

Ryan had terrible experience in barriers in So. Calif. 8 years ago, that took me way too much time to unravel and clear the way to access. And despite my absolutely clear warnings not to give him a certain anesthetic, of course they did, and subjected him to life threatening nausea/vomiting because of the physical position they left him in. Since then we pushed the anesthesiologist to tell us exactly which drug(s) he used, and had them added to his IPP (I believe) and other docs as DO NOT GIVE warnings. Could only get access in the next county after all that. And only after fighting with the insurance company as they would only pay for anesthetic in a medical facility - when then didn't do dentistry!

Now he has cleanings every 6 months (one paid by DDS, and one by us) to better keep on top of any developing cavities (only 1 or maybe 2 since then), which he is able to tolerate filling without anesthesia. They do give him some kind of sedative I think to relax his auto reflex, and give the dentist room/time to do what they need to do. And they don't tilt him far enough back to risk aspiration.

We also had another earlier experience at Rancho Los Amigos with dental work under anesthesia where again, despite my very clear warnings not to leave him on his back after anesthesia (due to aspirating risk), I walked into a ward (he was at the end) with him on his back, throwing up, as far from the nurses station as possible after they had promised me they would keep a close eye on him. I had to raise holy hell to tell them they could not do any more dental work under anesthesia without me present in the recovery room. It broke their policy but better than Ryan dead! There are LOTS of stories out there, especially with families with folks w/ CP or autism.

### **Story #6**

My son's name is Nick. Nick is now 22 years old and is diagnosed with PDD-NOS/Autism and moderate mental retardation. He functions at the level of a preschooler. We live in Sacramento County.

Dentist appointments have always been challenging for Nick. We have dental insurance through my husband's job but it does not cover any sort of dental anesthesia. When Nick was small, I took him to a pediatric dentist who basically shined a flashlight into his mouth and said his teeth were okay. I decided to find a new dentist who would actually do something. I took him to a dentist that said they could do a dental exam under anesthesia in an outpatient clinic. We did this but the dentist did not have any way to x-ray or do any major dental work. I decided to try another dentist. We used this dentist through his teen years. For most exams, Nick was strapped to a chair while someone would hold him down and keep his head from moving. A few times the dentist recommended that Nick be put under for some dental work. He brought in an anesthesiologist once a month to his office. We did this twice. It was not covered by our dental insurance and was out of our provider network for our health insurance so we paid \$1200 out of pocket both times.

When Nick turned 18, he got Medi-Cal so I called ALTA regional center and was told that only one dentist in the area took Medi-Cal for hospital dentistry. When I called the dentist office, they said not only were they majorly backed up with patients, they also would not see my son unless he had 2 dental issues. I decided to try something else.

On a whim, I decided to try him with "sleep dentistry" which basically is done under oral sedation. We have done this a few times now and it has been successful. The dentist visit is covered by our dental insurance but it is also out of network for our health insurance so we have paid for it out of pocket usually around \$400 each time. He has not had any major dental issues but if he did, I am not sure oral sedation would work and I would definitely like it done under general anesthesia in a hospital.

Thank you.

### **Story #7**

Daniel is a client of Alan Short Center and hasn't seen a dentist for years. He is 28 years old and has Fetal Alcohol Syndrome. He has a fear of the dentist. He was last seen in Sacramento at Dr. Bughao. He was so upset his blood pressure was high. Heartbeat was high. And he had a high fever because of the fear. I've raised Daniel since birth. He's had heart surgery, at 12 years of age and several other surgeries. He works hard to keep his teeth clean. But needs to be checked and cleaned. We don't know of a dentist to help Daniel. I'm his grandma.

### **Story #8**

Our children need dental more so than other children. I don't know how this is going to work. Concerned mom.

### **Story #9**

This issue is close to my heart because we just went to the dentist this month and was turned away due to my son's sensory issues. My son has happily gone to the dentist. He looks forward to the new toothbrush, tooth paste and gargle, he has no interest in the stickers or token toys. The dentist was content with visually looking at his teeth and had noted that they were "watching" a few areas at visits age 4 and age 5. They chalked his not sitting still for x-rays as pare for his age. At his 6 year old appointment they were no longer content with just visually looking at his teeth and after several attempts at getting x-rays taken they told me he outright refused to cooperate and that they had no other option but send him pediatric dentist which was not part of my dental plan coverage.

They did not understand that his reaction was not out of defiance but out of pain and freight of their use of the x-ray film. The film they use is plastic with sharp edges and to help fit it in his mouth they attach it to a hard plastic extension. I myself have felt major discomfort when they use it on my small mouth so understandably it would be equally painful for a kid with sensory issues. Luckily I asked the dentist for a referral and she noted my concern of the extra cost so she extended a referral to one of their other offices that could offer him a sedative, gas, to help ease his discomfort. I am waiting to hear back from the other office to set a new appointment and hopefully this will not incur me additional expenses not covered by insurance.

Update on my son's dental dilemma:

The office he was referred to informed me that they cannot use nitrous for x-rays, it is only used during the exam and treatment. They further referred me to a specialist dentist (kid's dentist) which was outside their group of providers. To not incur charges due to duplicate insurance claim I had to pick up the x-rays of his front teeth and take it to the kid's dentist. They were able to take his x-rays and found that he had four cavities between his back teeth. I could not afford to have his treatment done there. The filling of four cavities with nitrous would cost me \$263 at the kid dentist compared to \$110 at the dentist within my group of providers. After through contemplation I declined treatment at the kid's dental office and scheduled the treatment within my group of providers. I had to pick up the original x-rays of his teeth X-rays and coordinate the email of the additional x-rays before my son's appointment. Due to financial constraint we will be taking a chance going to a dental office he is not familiar with and not knowing if they have the patience to treat him.

In the midst of this process my son was approved for Medi-Cal and I found out the dental providers within my employers insurance cannot use Medi-Cal as a secondary insurance. Unlike my son's health care provider, Kaiser Permanente, who can use Medi-Cal as a secondary insurance. His health provider does not offer dental exams or treatments. I called the appointed Medi-Cal dentist and had a difficult time on their IVR decision tree (directed to multiple extensions with full voicemails and an operator extension leading to an invalid extension) by happenstance I was able to get through and set up an Intake appointment in September and was told appointments were all booked up until November to start treatment. Their offices would not offer nitrous on any treatments and they would have to refer me to a specialist for that. I asked if nitrous is a covered under Medi-Cal and they referred me to check my plan coverage. To date, I have only received an approval letter for Medi-Cal Dental coverage so I will need to find the resource to get that information. Upon approval for Medi-Cal health care coverage I received a welcome letter, coverage information, and a call from their new patients department. I did not have to seek out resources on my own. In many areas the Medi-Cal Dental coverage program needs to improve in their services and could use the Medi-Cal Health coverage program as a model.

Thank you for being a sounding board on service issues faced by special needs kids.

### **Story #10**

Zane went under and we had a hard time with insurance and getting bills! My other child, Brody is going under and will be in the hospital overnight because he has significant medical issues that the doctors worry about his lungs and the insurance and we are in fear of insurance problems again. We can't afford the bills. We are double covered; Medi-Cal and private insurance and we have more problems with that than anything else.

It is a true NIGHTMARE!

**Story #11**

I'm writing to express my dismay over the discontinuation of general anesthesia services in conjunction with dental care at Sutter Memorial Hospital.

My son, who was born at 29 weeks gestation and is now 24 years old, has chronic lung disease, cerebral palsy and autism. He is able to receive routine dental care in his provider's office, but when he required the extraction of his wisdom teeth, the only safe way to go about the procedure was under general anesthesia with intubation. He could not have safely had the surgery without being admitted to Sutter Hospital for the day and been under the care of an anesthesiologist and recovery room nurses.

Children and adults with disabilities may require general anesthesia for dental procedures – some because of complex medical conditions, some because they cannot tolerate sensory overstimulation and some who simply cannot sit still enough for the dentist to work.

Some of these patients would be suitable candidates for conscious sedation. I hope that option may be available at outpatient surgery center with staff trained to use conscious sedation safely.

**Story #12**

It is my understanding the Sutter will no longer be seeing individuals who need hospital dentistry under anesthesia. Clearly I know this isn't something you have any control of but how can we as parents have our voices heard? My daughter is 7 years old and has CP, hydrocephalus, osteopenia, seizures, feeding tube and is suctioned regularly...can you tell me where I can bring a child who is so medically fragile to have her teeth taken care of? We only get them cleaned once a year, although it needs to be done more frequently, that is all that has been covered in the past. We are also looking like she will need orthodontics in the future and I can't imagine how that will work in a regular office setting- can we write letters to Sutter? This is something that can't change for us- as driving to somewhere farther than Sacramento just doesn't seem like it will work for Sofia.

Please let me know how we can get our message to Sutter and hopefully make a change in their decision.

**Story #13**

My son is 8. He has a dual diagnosis of fragile X and autism. He is extremely sensitive to oral stimulation and has sensory processing disorder. Over the course of his life we have tried 3 different dentists who were unable to perform a complete cleaning or exam because it was so traumatic for my son. He simply could not tolerate the sensory overload experience in the dentist chair. We have had to use sedation hospital dentistry twice in the last 4 years. Without this medical service, my son would have extreme dental decay resulting in pain and infections. We are working with a behavior specialist to try and build lifelong dental hygiene skills but in the meantime, sedation dentistry in the hospital is our only option for cleanings and fillings.

Please consider the many children and young adults who simply cannot tolerate or comprehend dental treatment without being sedated. Thank you for your time.

#### **Story #14**

My son is 14 years old and was born with a chromosome abnormality accompanied by seizures and delayed learning and sensory issues there is no possible alternative to get him to sit still for dental procedures without anesthesia.

#### **Story #15**

Yes, my daughter needs Sutter hospital's care with anesthesia. She has required this service several times over the past several years and this change in service will be a detriment to her and to many other children I know. My daughter cannot tolerate any extended work in her mouth, due to movement, sensory and choking hazards. It is a shame that more and more medical facilities and practices are no longer serving this community. What are the parents to do now? The health of our kids is going to suffer.

Please keep us advised on this important issue.

#### **Story #16**

My son has received dental cleaning services through Sutter Memorial Hospital on several occasions. He cannot get his teeth cleaned like most people due to his disability and lack of understanding. Sedation dentistry outside of the hospital puts him at risk for breathing issues and death. If we cannot have his dental cleanings performed in a safe, controlled environment, we would not be able to provide him with dental care and he would be eventually lose his teeth and suffer from gum disease and other health issues which would be a result of poor dental care. We have both private insurance and Medi-cal which have paid for this service in the past.

I pray this matter will be able to be resolved for the sake of the thousands of consumers who rely on this service. Thank you.

#### **Story #17**

General anesthesia, as you are probably aware, is necessary to successfully address Sam's dental care.

Although we did go to Sutter Memorial for the procedure back when we first started, Sam is now seen at a surgery center.

So I am unclear as to what is happening. Is it just that using the hospital is no longer going to be an option but the surgery center(s) are still available? Or are you saying there will not be any location where this kind of dental care can be done?

#### **Story #18**

My daughter was diagnosed with mild to moderate autism at age 2. She is now 4. She recently had dental surgery. She had cavities that needed to be treated. I can't even imagine what it would have been like without the anesthesia! It was difficult enough just waiting for over an hour. She has sensory issues and she has a difficult time going to new places since she doesn't

know what to expect. She is nonverbal, unable to communicate her needs and wants. Please do not take anesthesia away from the people that need it the most! Imagine not being able to let the dentist know that you are in pain while doing surgery and they just overlook it even though you are yelling, crying, or kicking. There is still so much about autism that we don't know about and it's important to keep autistic children and adults as comfortable as possible in a situation they are already highly uncomfortable in. Thank you for your time.

#### **Story #19**

Please find a way to continue to provide the hospital dental care. I have twin sons, both teen-aged, who needs this kind of service. The last try for X-rays took 5 attendants to hold him down. With their sensory issues, they would need a general anesthesia to pass through the doors of the dentist office. I cannot be more serious about this. Please re-consider. Thank you.

#### **Story #20**

I have a teenager daughter with Down syndrome. She has always needed general anesthesia in order to have dental care. Without it, it will be difficult for dentist to work on her, and her oral hygiene will be deteriorated as she grows. General anesthesia has been so helpful in our daughter's situation, because it has prevented her from other diseases and more aggressive procedures.

#### **Story #21**

I was surprised to read that there was only one hospital in our area that was allowing hospital dentistry with general anesthesia and that this service would be ending. My daughter, currently 9-1/2, had hospital dentistry done in January 2013 at Kaiser South Sacramento facilitated by Kids Care Dental Group. She has Down syndrome and is not always very cooperative with dental treatment. She needed to have a good cleaning, 3 baby teeth extracted because the permanent teeth had come in, sealant put on her molars, and a good set of x-rays taken. This would never have been able to be accomplished in the dental office setting at the time. She was too uncooperative. Even now she would not have cooperated for that much treatment in the office. Hospital dentistry is something she will probably face again in her future at some point. We need to have access to these kinds of services in the Sacramento region for our kids. They deserve to have a healthy smile just as much as anyone else.

#### **Story #22**

My daughter, who is 9 years old and born with Down syndrome, has had general anesthesia for dental care several times. Without it she would not be able to get fillings, which would be detrimental to her health especially since she has heart problems. It is very important that she has great dental care and oral hygiene due to the heart condition. Any infection or lack of care can cause death. Further, it would stress her out way too much and scare her if she did not receive general anesthesia. She would require 5-6 people to hold her down while she cried and choked, etc. I know this because her dental office has tried on one occasion to not sedate her when trying to fill a hairline cavity. I am begging you as the parent of a child with special needs to please allow children such as mine to continue to receive general anesthesia for dental care.

These kids have it hard enough already. Why make anything harder? Attached is a picture I took of four people holding her down just for a cleaning in October 2013. Please reconsider keeping general anesthesia for dental care for children, teens, and adults with special needs who rely on it for their dental needs.

### **Story #23**

My daughter Grace has a history of 24 week preemie with oral aversion and malformed teeth. She has been hospitalized twice due to refusal to eat with stomach illness. If we removed her dental care without anesthesia, I'm sure we would end up in the hospital again. Even with the anesthesia, she did not eat or drink 9 hours after the procedure which was scary but manageable. These sensitive and medically fragile children need the anesthesia to prevent regression and medically fragile children from hospitalizations or further complicating oral aversion or sensory issues.

### **Story #24**

My daughter is 16 years old and has RTS (Rubinstein Taybi Syndrome). Due to her syndrome she is globally delayed. Her syndrome is also responsible for her having an extremely small mouth, overcrowded teeth, a highly arched palate, and an easily triggered gag reflux.

Ever since she was little we have taken her to the dentist every 6 months for her routine check-ups. She began without even allowing the dentist to look into her mouth, to now allowing a visual exam, brushing, flossing, and fluoride treatment! This is huge progress. Due to her mouth formation taking x-rays has not been successful unless done when under general anesthesia. We have tried, but it simply causes her to gag and ultimately vomit. Having bad dental experiences knocks us back down a peg in getting her to tolerate and comply to dental exams.

In 16 years Michaela has been put under general anesthesia about 6 times. Each time she has been able to have a complete exam, cleaning, x-rays, fillings, sealants and tooth removals (due to overcrowding issues). RTS causes small airways and issues with aspiration when under general anesthesia, as well as complications when waking up. I cannot imagine having to have these procedures done anywhere else but a hospital setting. It is simply too risky. The consequences are that her teeth would be overcrowded and painful causing gum disease among other things.

We have 4 children and have had to do laughing gas to get procedures done, so I know what I am talking about when I tell you that there is NO WAY Michaela would be able to tolerate such a procedure. Yes, booking a procedure like this in a hospital setting is time consuming and requires both mom and dad to take a day off work. Yes, it seems like a big process to get a teeth cleaning and possible fillings. But what is the alternative? For us and for Michaela there is not a choice. This is what is needed to give her the best quality of life possible.

Taking away the option for these kids (and adults) to have dental procedures done in a hospital is putting their lives at risk. It is making their care takers choose between what is comfortable or what is safe. Taking this option away is taking a big step back in time.

#### **Story #25**

My son has used dental anesthesia at Sutter Memorial when he needed dental work in the past. I know he will need it again because the dentist really tried to get him to stay still and keep his mouth open during the examination but my son just was unable to because of his Autism. Sometimes you just can't reason with children, and so yes I think anesthesia is only for children that cannot follow directions all the time due to disabilities but that option needs to be there. Otherwise I know what would happen to the children that cannot follow direction, they would not get the dental care they need because their parents would not let their child suffer.

#### **Story #26**

My son Andrew is in need of dental care. Andrew is a seven year old with Down syndrome. He has been to the dentist only three times and he could not even look in his mouth because Andrew does not understand what is happening.

#### **Story #27**

I just got the newsletter and saw the part about dental with anesthesia. I just scheduled an appointment with a Medi-cal dentist who is doing Gabe's dental under anesthesia at Kaiser. I have Kaiser insurance.

#### **Story #28**

We have survived without anesthesia, however, we should have been given the option at the very least. When Anker was younger, I would lay across his body and hold his arms down, another assistant would control his legs and another would hold his head as still as possible in a vice grip position. Anker would scream and cry through the whole ordeal so hard that he would burst the capillaries all over his cheeks. It was more like a torture scene from the TV show "24" than a dental visit.

#### **Story #29**

My daughter who is autistic at the age of 4 required a tooth removal. She was having a difficult time already just getting her to open her mouth at checkup and cleaning appointments. To avoid a traumatic scene for her sake the dentist suggested anesthesia, because just numbing her and her being awake would not have worked. To this day although she hasn't had to have fillings or another tooth removed (thank God) we still have to prepare her for any dental or for that matter doctor visit even today. My daughter is now 11.

#### **Story #30**

My 17 year old daughter lives in El Dorado County. She is diagnosed with seizure disorder, cerebral palsy, intellectual disability and other conditions. She cannot spit, and thus her doctors recommend that she avoid the use of fluoride toothpaste. We brush her teeth for her twice daily and restrict access to sugars, but she still gets cavities. She depends upon anesthesia

dentistry for dental care. While we would prefer that she not undergo general anesthesia, there are no other options available for dentistry. Given these facts, a decision to deny anesthesia dentistry without workable alternatives is a decision to deny dental care altogether for the most disabled among the developmentally disabled population.

### **Story #31**

My name is Robert, we live in Sutter County, we have 2 adoptive twin siblings , male/female, 15YO we have for many years now, for both children, used the services of Dr. Rodney Bughao DDS. we are perhaps the lucky ones, as we have private Delta Dental insurance as well as Medi-Cal ,however even then, it is a challenge to get qualified, Dr. Bughao has a large staff and it still takes a lot of time and effort, it's not at all like an issue with say, Blue Cross or Kaiser, both children have ASD, ,Mood disorder, OCD, and both have oral sensory issues, that compel the use of Anesthesia, we are seen on a 2-year basis for oral examination and cleaning, I shudder to think if one of them should need immediate dental care what would we actually do, in that scenario, that is to say, living in Sutter County and all?

### **Story #32**

My son, Ryan (14), is autistic and does not cooperate at the dentist very well despite numerous practice sessions with his ABA therapists. We have only recently been able to get him to sit still for the x-rays and a very light teeth cleaning. He has needed cavities filled and teeth pulled since his baby teeth had strong roots and would not come out on their own. There is no way this could have been done with just Novacane in the dental office. He would never sit still for that or cooperate with the dentist. The sounds of the equipment alone is excruciating for him. So he has always needed to go to the hospital and be put under general anesthesia for the dental work. This is quite the ordeal for him but the work gets done easily and is less traumatic for him. Without the availability of going to the hospital, I just don't know what will happen to him now. He deserves to have proper dental care for his needs. I sincerely hope a solution is found before he needs dental care again. We live in Placer County.

### **Story #33**

It's imperative for good dental cleanings. My son has no diagnosis to this date and we tried going to a regular dentist who made a lot of accommodations just for my son, even scheduling him at a time of day where he would be the only one in the office as he would sometimes scream and become combative and we did not want to frighten the other children. The method in which we were only able to clean off some of the plaque on some of his teeth took a minimum of four people. My son would lay on the chair. There was the dentist and the dental assistant who would hold the mouth prop in place, also requiring it to be covered with a protective plastic as my son is allergic to latex, then there was my husband who would lay his body over the lower extremities of our son, of course he had to be barefoot as the kicking would start and then I would lay over my son's upper body and hold him firmly still continually telling him I love him and how good he was doing. We could never clean more than the four lower teeth. X Rays were impossible, no brushing and no flossing. Due to my son taking medications for his sleep, which cause dry mouth and being a mouth breather, he gets plaque on his teeth in a few weeks later.

Sedation dentistry in the dentist office is very dangerous and puts our children and adult children at risk for complication and even death. We never know how they will respond to the sedation. Yes, these are our teeth and we must weigh out the danger for more life threatening surgeries, which our children go through from time to time. It came to a point where my son was too strong and it became extremely dangerous for him to have his teeth cleaned in the dentist office. The sharp tools could catch him in the eye or the others assisting as his hands got free from under my body.

We had his teeth cleaned by Dr. Bughao several times and then my son got ill and we had to delay some of his dental cleaning to deal with other health matters. At the point where our son could finally get his cleanings done we were informed of this deleted service. Dr. Bughao has been performing this service for years and is the only individual in town who does. He finally was able to train someone and get them on board with him as he knows one day he will retire and he knows the value of this needed service. It has been almost two years since we have seen a dentist and it has been over three years since we have had hospital dentistry performed. I am very concerned that this service is no longer available and I feel it will put many of our family members at risk. Do I want to take a chance with a dentist who performs sedation dentistry and lose my son to a medical error. The answer is no. My son cannot talk and he hits his head a lot and screams and I wonder are his wisdom teeth bothering him. I do not have this answer. This answer will not be available to me without hospital dentistry. My son has off the exchange private health care and medical as secondary. Why do I pay for private health care when he can get coverage for free with medical, because I want quality care.

I hope this matter will be resolved in a compassionate way for the health care workers and consumers.

### **Story #34**

My son sees Dr. Mark Choi in Woodland – we will have our 6<sup>th</sup> dental service under anesthesia in November. Our first and second dental under anesthesia was with Dr. Mandelaris' office – the second time the dentist was so helpful she removed 8 teeth because they were baby teeth and would fall out one day – it took 2 years for his teeth to all come back – we never went back. We then found Dr. Choi and while we do go to his office twice a year – he cannot do anything in the office without creating a huge meltdown and becoming an overload for my son. We did try to give him Lorazepam and he ended up in the ER for 10 hours while he was coming off the medicine – he had a bad reaction and it was like he was loaded on cocaine or something. My son has dual dental insurance with Delta Dental and medical insurance with WHA – we are lucky that his services are paid for almost in full – we might have a very small dental balance – the issue is all local dentist charge a fee to the family for using the Surgery Center at Woodland Healthcare. I call this fee – a slap in the face and I am going to charge you \$300 to walk across the street. We are required to pay this fee prior to services. If my son did not have autism we would be able to go to a dentist like all others and not be charged a screw you fee. I actually filed a grievance with Delta Dental – it did not get approved but I did make my case and Dr. Choi is aware of how I feel. My son still needs the services so I will find a way of paying this fee.

**Story #35**

My adult daughter has Fragile X Syndrome and I live with and care for her in Marin County. She is a Regional Center client and has Medi-Cal.

While in her early teens, she has required general anesthesia for wisdom teeth extractions and a baby tooth extraction in preparation for braces. The private practice orthodontist who performed the wisdom teeth extraction did not accept Medi-Cal, so I paid out of pocket for the entire procedure. UCSF did the baby tooth extraction (it never fell out) and the entire cost was covered by Medi-Cal.

For years she's been going to the County Dental Clinic on 4<sup>th</sup> Street in San Rafael, where student dentists are doing on the job training to complete their degree, overseen by a licensed dentist. She's only had 3 fillings in her life, all done at this clinic, and although the first two were years ago and went fairly well, (she was scared, but not inconsolable) she became inconsolable during her most recent filling last month. This was due in part to the student dentist not knowing how to handle her special needs, and although I was in the room with her, trying to console her, she was traumatized...she went into full body tremors and couldn't stop shaking, even after I covered her with a blanket. (Next time if her cries sound like screams and she starts to go into shock like that, I'll insist the dentist stop what he's doing and allow her to calm down before continuing!).

She was scheduled to have two small fillings done on that day, but she was so upset, (as was everyone within earshot,) he only did one and suggested next time she have nitrous gas. (I don't know why he didn't stop and give it to her when she went into shock.) I agree, and asked if she ever needs more complex work done, would they provide a general anesthesia, and they said "no".

I believe it's necessary for Medi-Cal (or another agency) to provide the general anesthesia option for disabled patients requiring it. If the county clinic is not set up for general anesthesia, then an appropriate clinic, with fully-licensed staff, would be required, of course.

Before my daughter's next and future dental appointments, I'll request nitrous and for the licensed dentist to help her while the student looks on. The staff needs to be better trained to handle patients with special needs. Even the x-rays and cleaning are extremely distressing for her –and for everyone else! Thanks!

**Story #36**

We have a daughter with Bainbridge Ropper Syndrome. She is a 10 year old girl. And we took her to her dentist to do a normal cleaning and the doctor said that the only way to do her cleaning is under anesthesia. But the cost of that needs to be paid for by us. This was 2 months ago and we are still waiting for the office doctor to call us for an open day to do the job. So, yes, this is what our short story is about our family.

### **Story #37**

My story is quite extensive, but I will do my best to keep it short and sweet. As my disability causes significant muscle contractures, my jaw hardly opens wide enough to put in a fork with food, let alone a toothbrush to reach my back molars. When I was in my thirties, I had an upper back molar break and there was no way a dentist could get in there to fix it. For previous fillings and such they often used a pediatric drill bit and did their best to stretch my mouth, but as I age, it became impossible. So with the broken tooth, I was sent to an oral surgeon and they were going to do the work at a hospital dentistry clinic (Loma Linda located in Southern California), but since I was such a high risk for anesthesia, it was decided that it needed to be done in the hospital. In addition to the anesthesia here, it was necessary to actually break my jaw to open wide enough for the work. Regretfully, I do not remember the dentist's name as it was some time ago. Though we tried stretching exercises to keep the jaw flexible, it only resulted in an abscess and eventually healed tighter than it was originally. In 2008, I had another significant cavity in a back molar and once again, I had to be admitted to the hospital, undergo general anesthesia and thankfully, they did not have to break my jaw, but they did have to do some extreme stretching, which I could have never tolerated awake or with local anesthesia. This occurred while I was living in Sacramento and it was a nightmare trying to pull it all together. My dental insurance did not cover such a procedure, so I had to rely on my medical insurance, which was Blue Shield and I was in the UC Davis System. They of course, had no hospital dentist and so the search began. I did find a hospital dentist, who would do the work, but I also needed an oral surgeon, who would do the jaw surgery, and the process of finding both with hospital privileges at the same hospital, which could be covered by my insurance was quite a process. First I had to get approval from my insurance to go outside of my usual provider, then each of the dentists had to figure out how they were going to get privileges for the hospital to do the work. After months of working with all three entities, we finally had everything arranged and I was taken care of at Sutter Memorial. Regretfully, I don't remember his name either, though he was a remarkable dentist and worked mostly with people with disabilities. I do remember he was out in El Dorado Hills I believe. The main thing here is how very important hospital dentistry is to those of us with significant developmental disabilities; be it physical access, behavioral problems, inability to handle regular dental procedures, it is critical that we receive the necessary care we all deserve. Dental pain is really one of the most severe types of pain to deal with and of course, dental work is some of the most costly there is, so I'm hoping that after so many years, things will start to improve, rather than go downhill.

### **Story #38**

My son, DJ, is 19 years old and had Down syndrome, autism, heart problems (both congenital and acquired), chronic lung disease, emphysema, reflux, had a year-long time of being "trached" and vented when a baby and is gastrostomy tube fed. The doctors tell us he is "medically fragile".

Because of all the tubes and medical interventions in and around his mouth, DJ has developed a strong oral aversion, not letting anything into his mouth without it being forced and when it was forced he would gag and vomit repeatedly. One of the tests he underwent, a biopsy of his

lung tissue, showed that DJ had aspirated in the past, something that all his doctors had felt should not happen again and so they warned us not to do things that might induce his vomiting.

I was at a loss as to what we would do for dental care. I worked on making “tooth brushing time” pleasant and fun, but our meager attempts at introducing a musical toothbrush and demonstrating that it made pleasant sounds as it was brushed on DJ’s hands, arms and near his face were no remedy to the gagging and vomiting that ensued when we tried to come near his mouth. Meanwhile, plaque was building up on his teeth at an alarming rate untended and unbrushed and his little teeth were representative of many with Down syndrome with their odd and often twisted placement in his mouth. The doctor explained that because of DJ’s reflux and being G-tube fed increase the amount of plaque that would accumulate. At the time, we lived in Humboldt County and the only remedy offered was the services of a therapist who encouraged us to force DJ’s mouth open wedging tongue depressors wrapped with tape between his jaws and forcibly brushing his teeth. Somehow this didn’t jive with the advice of the medical doctors who told us not to induce vomiting which may cause aspiration and worsen his chronic lung disease.

About this time we moved to the Sacramento area and we met a now host of providers and support agency personnel to whom we voiced our dental concerns. Those concerns brought information about Dr. Bughao and the sedation dentistry what was available for children like our son.

DJ finally had his first visit with a dentist at age 3 after we had moved to the Sacramento area and it was done under sedation at Sutter Memorial Hospital. We had finally found the answer to our son’s need for dentistry. From that time on, about every 2 years, DJ underwent sedation dentistry to clean his teeth and to check for any needed dental care.

We always found Sutter Memorial to be a comfortable and responsive place to have our son’s dental care provided and Dr. Bughao became a trusted ally in providing care for DJ.

DJ continued to have difficulties with allowing anyone to examine his mouth, and he experienced more medical challenges through the years: a second open heart surgery at age 5, a bout with H. Pylori around age 12, and a life long battle with reflux and a continued need for g-tube feedings. All of these difficulties complicate and support the need for having teeth that are cleaned regularly and given good dental care.

Each time we planned for a dental visit we were always grateful that it came with a careful call from the anesthesiologist who would be overseeing our son’s journey into sleep and back out while receiving dental care. Because DJ had had so many surgeries, had both heart and lung problems, this call always helped to assure us we were receiving the best care possible to ensure DJ’s waking up at the end of his procedure.

Some notable things have happened when DJ has undergone sedation dentistry. One time someone did not arrive with the proper paper work and so they were “bumped” from the schedule set for the day and we were asked if we would be willing to move up to their slot from

our later time. It was explained to us that the OR was an expensive facility and that they needed to fulfill their time obligations and our willingness to “go early” would help them to meet those obligations. We readied ourselves and off DJ went.

Then there was the year that DJ’s dental visit coincided with Halloween. I enjoyed all the costumes and festive decorations and attitudes, but DJ seemed to take it all in stride and didn’t seem to notice the festive changes, but I laughed about my little “pumpkin” turned jack o’lantern following his sedation dentistry as he smiled to reveal a few new gaps in his teeth as baby teeth were refusing to exit causing more crowding for permanent teeth and needed to be removed. It brought home to me that day the blessing of being able to have dental care for my son, who needed so much more than what a typical dentist could provide.

And then there was the time that DJ’s breathing, after receiving a dose of preoperative sedative, began to slow. It slowed to the point that I became worried and called attention to it from the nurses who were with us in the ambulatory care unit. I had come to know that providing anesthesia to people like my son could be tricky business. But the team rallied around quickly and provided the care and support that DJ needed to breathe properly. How thankful I was that day that they were close by and had the skill and experience to know what to do in that situation!

It concerns me deeply that Sutter is choosing to close its doors to the type of sedation dental care that my son needs. At our last visit for DJ’s dental care we had been discussing the need for more frequent cleanings with DJ’s cardiologist and with Dr. Bughao due to the overgrowth of plaque that forms in DJ’s mouth due to his reflux and G-tube feedings, causing DJ pain and undue risk of infection. And now we are faced with having nowhere to go to even receive care for our son. Because of DJ’s health history and ongoing medical, behavioral and developmental concerns he truly needs sedation dentistry. DJ needs to have a skilled and experienced anesthesiologist available to him to oversee his procedures. He needs a dentist who has experience and compassion. Because his insurance is Medi-Cal and is managed by Partnership Health in Yolo County, DJ’s options are limited and DJ is left without remedy. I hope my son’s story will help to ensure that dental care for DJ, and people like him, will again be available in our part of California. West Sacramento.

### **Story #39 and #40**

I am a medical consultant for Redwood Coast Regional Center, and have two stories from Mendocino County, where access to an OR is particularly bad.

One: TU is an adolescent man with autism, and is quite large and powerful (6’4", and 300 lbs). He was known to have a dental abscess and was referred to UOP for treatment under general anesthesia. He waited more than one year for an appointment for his dental surgery. His behavior became so aggressive that his mother requested an out-of-home placement. An "emergency" appointment was rapidly negotiated in a private hospital, treatment was delivered, and the request for out-of-home placement was withdrawn. Multiple phone calls to UOP to expedite his treatment were fruitless--they had a long queue of waiting patients.

Two: WS is a 58 year-old man with intellectual disability and poor communication skills. He stopped eating, and seemed sick, and developed a fever. He was admitted to the hospital in Ukiah, and was treated for sepsis with IV antibiotics, improved, and was discharged. Within one week, he was re-admitted with severe infection again, this time with jaw swelling, and an obvious dental abscess and cellulitis. He was again treated with IV antibiotics, developed C. dif diarrhea (a consequence of aggressive antibiotic treatment), and was again discharged with his infected tooth still in his mouth. Three weeks later, he finally had the tooth removed in the OR under general anesthesia, and eventually recovered. By the time he was treated, he had gone 6 weeks without eating, and had lost about 30 pounds.

I'm sure there are more, but these two stories led me to present to the Human Rights Committee, which was powerless to intervene.

I hope we are able to muster resources to solve a pretty serious problem.

#### **Story #41**

7 year old with Autism, seizure disorder, asthma, developmentally delayed. First took child to general dentist in 2012. Patient was unable to follow direction from dentist due to disability. Dentist tried to get a visual to diagnose and patient was uncooperative wouldn't sit still. Wouldn't open mouth. Patient gets very overwhelmed going to doctor's office. Dentist referred family to our facility. Uncle is very appreciative for our facility. Up to this point he has not had trouble obtaining medical or dental care with Medi-Cal. Merced County (story shared with dental surgery center staff orally).

#### **Story #42**

Regarding 12 year old with Cerebral Palsy, Linear nervous syndrome, developmentally delayed. About 2 years ago mom took child to a general dental office. Due to child's disabilities it took 4 people to hold child down for just a cleaning. Doctor explained to mom that he would not be able to treat patient anymore. He felt like it was a form of torture (holding her down). Mom has made several attempts to call health plan of San Joaquin and left several messages, and no one has returned her calls. Stanislaus County (story shared with dental surgery center staff orally)

#### **Story #43**

Regarding 21 year old with CP. Back in 1999 mom took child to dentist due to child having CP and dysphasia (unable to swallow) patient was referred to many facilities as far as San Francisco and due to child's insurance she was unable to be treated. Not until VMRC was introduced child was referred to CCDS. Due to the dysphasia patient needs constant suctioning to avoid aspirating pneumonia. Mom now lives in Manteca n had tried to find a facility that can meet the needs of her daughter and to no avail. Many times dentists don't see special needs patient or use any sedation. San Joaquin County (story shared with dental surgery center staff orally)

#### **Story #44**

Regarding 21 year old with CP, Autism Spectrum Disorder. Kyle was born premature and was diagnosed with CP. The part of the brain that was affected was the frontal. Kyle's development was extremely delayed and he became a client of VMRC at the age of 9 months. I am Kyle's grandmother and a co-conservator along with Kyle's mother. No one knows Kyle better than his mother and I. We have been Kyle's advocate from day one.

We find it extremely frightening that people who do not know our special needs children and young adults can sit and make judgments about their health issues that you can determine behind a desk and looking at a piece of paper that an individual does not need the extra care to be put under anesthesia for dental work. How do you know? Are you just looking at the cost? Do you think as parents we want to have our special needs people put under anesthesia with all the risk factors that it entails? No we do not!

Have you gone online and checked to see how many dentists that accept Denti-cal are accepting new clients? Then on top of that are qualified to work on special needs clients? Zero! We have tried to take Kyle to a regular dentist. The results are it is an out of pocket expense of hundreds of dollars and Kyle cannot keep his mouth open for any length of time on his own. Kyle becomes so upset that he has a panic attack and it is very hard to work on him. Central California Dental Surgery Center has been a godsend for all of us, especially Kyle. Kyle had his wisdom teeth taken out last year. Most people have to be put to sleep for wisdom teeth extractions. Unless you have a special needs person that you care for you cannot deny the anesthesia part for these clients.

#### **Story #45**

Regarding 29 year old daughter with Severe Microcephaly and CP in San Diego

I have so much sadness. Megan has been crying since August. Megan is non-verbal and I have almost had every medical problem checked off. Since August, Megan has been waiting to have a Deep Teeth Cleaning. Megan's mouth is swollen, red and she pops her jaw crying all the time. Megan was always easy going - not anymore. Something is terribly wrong. I took Megan to Dr. Adams in San Marcos, August 19th. Medi-Cal denied Megan on September 18th due to no x-rays for a Deep Teeth Cleaning. It's ludicrous to sedate Megan for x-rays and then another date to sedate Megan again for the Deep Teeth Cleaning. Megan has not had a Deep Teeth Cleaning in 5 1/2 years. Dr. Adams requested San Diego Regional Center to pay for the Deep Teeth Cleaning. It was approved last week. Dr. Adam's office has not received the paperwork yet. I need to be patient. They are already booked to December. Megan has a very small mouth and too many teeth Dr.. Adams talked about removing a couple overlapped teeth. Megan's intelligence is between 3 months to 6 months. I have always been able to fix anything. Not with Dental Problems!!! For 30 years, my husband and I have paid for a private individual medical policy PPO. I feel safe that I have always been able to provide the Best Medical Coverage for Megan. The expense is extremely high! We have never had Dental Coverage. It is ridiculous that a human being has to wait months for care. Is this civilized??? Every day I am taking care of Megan. How do we think this is okay??

Megan had a Baclofen Pump Surgery last year, 2013, due to too much anesthesia. Megan was in ICU at the Children's Hospital. Megan list her IV's within two days. Megan was overdosed a week later on too much Baclofen. Megan was near death. After twelve long days, we took Megan home. I pray to God that Megan doesn't ever go through that experience again. I feel extremely safe with Dr. Carl Miller. He is a traveling anesthesiologist. I have paid him for Megan's two Implants and Megan's wisdom teeth to be removed. Financially, I'm in severe debt! I don't want Megan's life in danger. Megan is going to be 29 years old on 11/15/14. Who should be responsible for her needs?

I was searching for a dentist to treat Megan in 2011. Dr. Henry Chamber's suggested Loma Linda University School of Dentistry. I actually drove there and Megan wasn't ever examined.

Megan has a tragic accident with St. Madeline Sophie Center Day Program in San Diego in 2012. She had one front tooth knocked out and the other front tooth cut through the skin above her lip and then jam into her jaw bone. Through time, the tooth came down dead. I mailed bills to Megan's lawyer, and months later, I would receive payment. The last bill for the two implants took one year and eight months to be reimbursed.

Megan needed a Deep Teeth Cleaning but was having too many issues that she had to deal with.

No dentist, two teeth knocked out, two life threatening medical issues, a court case against St. Madeleine Sophie Center, her wisdom teeth and NOW, a desperate NEED for a Deep Teeth Cleaning.

I think Megan has suffered enough!

Sincerely, Megan's mother

#### **Story #46**

Our concern with the current situation of a shortage of hospitals allowing Anesthesia Dentistry is that we have a 5 year old son with Down Syndrome who will need dental work. Our son has sensory processing issues and completing simple dental maintenance has proven to be challenging because of it. Completing major dental work will be next to impossible without anesthesia. We are very concerned that we really need to have the right professionals (Anesthesiologists) with the right environment (a hospitals with the right equipment) because our son has had anesthesia on a couple occasions for simple medical procedures and both times he had a reaction to anesthesia that caused his heart rate to drop dramatically. His heart rate dropped dramatically to the point where he had to have Atropine administered to get his heart rate back up. After the second incident, the anesthesiologist told us to NEVER allow our son to undergo anesthesia without having the proper professionals with our son in a "hospital setting. That even in a surgical center the result could be catastrophic." A dentist office is surely not an appropriate setting for our son to undergo anesthesia and if there are no options for hospital dentistry then our son has no options to have his teeth worked on.

We would ask that you take this type of situation, which I'm sure applies to many other families, into consideration as you discuss this very important topic.

Thank you for your consideration.

Sincerely,

Richard and Irma Wirick (Submitted 3/15)

#### **Story #47**

My name is Kim Christensen & I am the mother of a 16 year old daughter with severe autism & MR. We have been using anesthesia dentistry since she was 6 years old.

I know one dentist that practices anesthesia dentistry. ONE.

He is the most wonderful, caring & compassionate dentist that you could ever hope to treat your child. Anytime my friends ask if I know of a dentist for their child, his name is the one that I give them. He is booked up MONTHS in advance, and his practice keeps relocating further outside of the greater Sacramento area due to hospitals cancelling this service because of lack of funding.

If your child needs emergency treatment and is in severe pain, your child will have to wait, often for weeks if not longer. It's hard enough for typical children & adults to endure chronic pain, but for the population of adults and children with special needs, it's unbearable.

Please, I am urging our legislators to solve this reimbursement issue and provide access to this critical health care.

Thank you,

Kim Christensen, Granite Bay, CA (Submitted March 2015)

#### **Story #48**

My son, Ryan, age 14, is autistic and does not cooperate at the dentist very well despite numerous practice sessions with his ABA therapists. We have only recently been able to get him to sit still for the x-rays and a very light teeth cleaning. He has needed cavities filled and teeth pulled since his baby teeth had strong roots and would not come out on their own. There is no way this could have been done with just Novocaine in the dental office. He would never sit still for that or cooperate with the dentist. The sounds of the equipment alone is excruciating for him. So he has always needed to go to the hospital and be put under general anesthesia for his dental work. This is quite the ordeal for him but the work gets done easily and is less traumatic for him. Without the availability of going to the hospital, I just don't know what will happen to him now.

I know that it is difficult to find a Dentist that will take Denti-Cal and work with our kids with special needs. Most dental offices tell me it is because there is too much paperwork and it takes a long time for them to receive payment. This area also needs improvement.

My son deserves to have proper dental care for his needs. I sincerely hope a solution is found before he needs dental care again.

Roseville, CA (Submitted March 2015)

#### **Story #49**

My daughter, age 12, was diagnosed with autism in 2010. We have had to use this type of dentistry to have a tooth pulled; otherwise it would have definitely traumatized her. I haven't experienced being denied this type of service but I totally support your agenda and I will definitely be at the capital on March 17<sup>th</sup> to stand with you. The powers to be do not realize how many kids and adults and their parents are affected (and continue to be) by autism and the services they will be needing for the rest of their lives. Thank you for all that you do.

Andrea, Sacramento (Submitted March 2015)

#### **Story #50**

My son Isaac is 22 years old and requires anesthesia in order to receive dental care. He has been disabled since birth with Cerebral Palsy. No dentist or hygienist has been able to give him a routine cleaning or x-ray without first placing him under anesthesia. Over the years we have spaced out his hospital visits to every three years so it is not like we are abusing the system. We have had to travel as far as UCSF in order to receive this service. Most recently, when Isaac turned 18, he was able to get hospital dentistry at Sutter Memorial Hospital under the excellent care of Dr. Bughao. We were recently told that Sutter Memorial was no longer going to allow him to see Medi-cal patients there for dentistry. This is not OK. Where are we supposed to take our son for treatment? While we cannot make the hearing, please know we are concerned about Isaac's dental care and how he will be able to receive his treatments in the future. Thank you for speaking out on his behalf.

Dana, Sacramento (Submitted March 2015)

#### **Story#51**

I am a mom with a little girl with autism. Charlotte-Rose needs anesthesia when she has dental work done. Because of her autism, she is unable to sit still for very long, and since she does not understand what is going on, hospital settings make her very scared and anxious. Charlotte-Rose is 5 years old. In order to get dental work done for her, we have to drive to downtown Sacramento. She has received dental work twice for cavities, and it's never fun. It wouldn't have been possible for the dentists to do what they needed to do without the anesthesia. Charlotte-Rose is nonverbal. By the time we know she needs dental work, it's usually pretty serious since she is not able to communicate with us that she is in pain until it gets bad enough to where she is crying and we just know something is not right. Each time we went to the dentist for the prior surgery appointment, we could barely get her to open her mouth long enough to where the dentist could even see that she had a cavity. Sheila, Sacramento (Submitted March 2015)

